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Self-efficacy, psychological adjustment and decisional-balance regarding decision making for outpatient chemotherapy in Japanese advanced lung cancer

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This study examined the application of the trans-theoretical model (TTM) for readiness for decision-making of outpatient chemotherapy of Japanese advanced lung cancer patients by a cross sectional questionnaire survey. A questionnaire was conducted with 105 Japanese patients diagnosed with advanced lung cancer receiving chemotherapy. We classified them according to the TTM stages, including 4 in precontemplation, 42 in contemplation, 22 in preparation, and 35 in action. The valid model ($\cdot^2$ (37)$\cdot$ 42.56, p$\cdot$ 0.24; GFI$\cdot$ 0.93; AGFI$\cdot$ 0.88; CFI$\cdot$ 0.98; RMSEA$\cdot$ 0.04; AIC$\cdot$ 100.56) derived from structural equation modeling (SEM) revealed that stage of outpatient chemotherapy was significantly affected mostly by decisional-balance ($\cdot$ $\cdot$ 0.60, p $\leqq$ 0.001) and partially by time from the patient's house to the hospital ($\cdot$ $\cdot$ $\cdot$ 0.15, p $\leqq$ 0.10), and that decisional-balance was significantly affected by self-efficacy ($\cdot$ $\cdot$ 0.48, p $\leqq$ 0.001) and nausea ($\cdot$ $\cdot$ $\cdot$ 0.23, p $\leqq$ 0.01). The findings from our study provided encouraging results for adopting the TTM in decision making for outpatient chemotherapy in Japanese cancer care and several clinical implications were obtained from the results.

Keywords: trans-theoretical model; decisional-balance; self-efficacy; outpatient chemotherapy; lung cancer

Introduction

Advanced lung cancer carries a poor prognosis and requires treatment with chemotherapy. Recently, improvements in the quality-of-life (QOL) of advanced lung cancer patients has become essential for good cancer treatment and care (Bottomley, Efficace, Thomas, Vanvoorden, & Ahmedzai, 2003; Ishihara et al., 1999). Supportive care in cancer treatment at home, especially is important for their QOL (Sakai, 2002; Tsukagoshi, 2002). In western countries, outpatient lung cancer treatments are common, but in Japan most patients receive treatment in hospital (Sakai, 2002). One of the reasons for this difference

may be the requirement of Japanese national insurance system that chemotherapy is administered in an inpatient setting. Recently, the Ministry of Health decided to allow insurance payments for outpatient chemotherapy for cancer patients (Sakai, 2002). In Addition, Japanese oncologists have recognized the importance of outpatient chemotherapy for lung cancer to improve the patients' QOL and have started to recommend such outpatient services for their patients (Asai, Minami, Komuta, & Kido, 2000; Chohnabayashi, Uchiyama, Nishimura, & Nasu, 2004; Kawasaki et al., 2003) and several cancer centers have started outpatient clinic centers for cancer patients (Kobayashi & Kobayashi, 2000).

However, patients are still reluctant to make a decision to go home and receive inpatient treatment instead. One reason for reluctance of the patients may be the strong psychological influence on their decision making process. To develop support systems for the patients, clarification of this psychological mechanism is needed. Thus, we tried to apply a framework and a theory from psychology to clarify the patients' decision making process in the transition from inpatient treatment to outpatient treatment.

In health psychology and behavioral medicine, several theories and models have been developed to account for health behavior. Among these, the trans-theoretical model (TTM) (Prochaska & DiClemente, 1983) is useful to explain changes and has been adopted in not only health problem settings such as several studies of smoking cessation (Prochaska & DiClemente, 1984), but also various health behaviors. For example, in the area of cancer medicine, TTM has been applied to examine compliance in health screening for colorectal cancer generic testing (Manne et al., 2002), and mammography adoption (Lauver, Henriques, Settersten, & Bumann, 2003; Rakowski, Fulton, & Feldman, 1993). We believe that application of the TTM to examine patients' behavior and the intention to receive chemotherapy after transitioning from inpatient to outpatient status will be very useful to clarify the psychological factors underlying the patient decision making process for outpatient chemotherapy.

In addition, in the TTM, the function of self-efficacy has an important role in the stage of change, and mediates between the intention for behavioral change and actual behavior (Prochaska & DiClemente, 1984). Several studies have pointed out that self-efficacy has a great impact on psychological adjustment, including the anxiety and depression of advanced cancer patients (Beckham, Burker, Lytle, Feldman, & Costakis, 1997; Hirai et al., 2002; Lin, 1998; Merluzzi, Nairn, Hegde, Martinez Sanchez, & Dunn, 2001). It is hypothesized that self-efficacy and psychological adjustment may correspond to the readiness or stage of change for outpatient chemotherapy. Thus, self-efficacy may indicate the possibility to develop psychologically-oriented interventions for patients who would benefit from outpatient chemotherapy.

Thus, this study attempted to examine the readiness for outpatient chemotherapy of advanced lung cancer patients in Japan using TTM. In particular, the attempt was focused on the function of self-efficacy and psychological adjustment in terms of the readiness for the treatment. Finally, we discussed the clinical implications derived from our results.

Methods

Participants

The participants were consecutively recruited from one specialized hospital for chest disease using convenient sampling from March 2003 to July 2003. The sample was

composed of 105 Japanese patients diagnosed with advanced metastatic lung cancer, who were inpatients and outpatients receiving chemotherapy. All patients without dementia or delirium were informed of the aim and methods of this study, and their written consent was obtained.

Measures

We developed a questionnaire with a face sheet and four psychological measurements. The face sheet included questions regarding each participant's background, including age, gender, and knowledge and past experience of outpatient chemotherapy.

In a previous preliminary interview study (Hirai, Tokoro, Naka, Ogawara, & Kawahara, 2005) and preliminary analysis (Arai, Hirai, Tokoro, & Naka, 2006), we developed two psychological scales based on TTM: A single item to measure the stage of readiness and a decisional-balance scale for outpatient chemotherapy in lung cancer patients. A single item to evaluate patients' stage of readiness included four alternatives for stage of readiness: Precontemplation ("I have no interest in receiving outpatient chemotherapy."), contemplation ("I have been thinking that I might want to receive outpatient chemotherapy."), preparation ("I am preparing to receive outpatient chemotherapy."), and action ("I have already received outpatient chemotherapy."). This item was proved to have content validity through the content analysis of interview data (Hirai et al., 2005). The decisional-balance scale of outpatient chemotherapy is a 20-item scale with two subscales: Pros and cons. The pros consisted of 10 items: Freedom of movement; comfortable environment; increased relaxation; increased social support; freedom of time; psychological stability; regarding oneself as an ordinary person; fewer time restrictions; decreased concerns; treated as an ordinary person. The cons also consisted of 10 items: Worries about instability of illness; dissatisfaction with consultation time; worries about insufficient treatment; lack of enough nursing; worries about side effects; insufficient facilities for treatment; worries about urgent treatment; lack of information from peers; less communication with medical staff; less medical information. Each subscale of the decisional-balance scale has been shown to have high reliability (Cronbach alpha• 0.88 for pros and 0.87 for cons) and high structural validity by confirmatory factor analysis ($\bullet^2$(166)• 223.73 (p ≤ 0.001), GFI• 0.83, CFI• 0.93, RMSEA• 0.06) for the two-factor structure which was hypothesized from the results of our interview study (Arai et al., 2006).

The scale of the Self-Efficacy for Advanced Cancer (SEAC) was designed to assess self-efficacy in terms of the illness behavior of advanced cancer patients (Hirai et al., 2001). It is an 18-item scale with the following three subscales: Symptom coping efficacy (SCE; e.g., "I can manage insomnia caused by pain"); ADL efficacy (ADE; e.g., "I can enjoy TV or radio programs"); Affect regulation efficacy (ARE; e.g., "I can maintain a positive attitude"). The scale is formatted on an 11-point Likert-type scale, ranging from 0 (not at all confident) through 50 (50% confident)–100 (totally confident). Each subscale of SEAC has been shown to have high reliability (chronbach alpha• 0.73–0.81) and high structural validity (GFI• 0.93–0.96; Hirai et al., 2001). The scale also succeeded in clarifying the significant relationships among physical condition, self-efficacy and psychological adjustment of advanced cancer patients (Hirai et al., 2002).

To assess psychological adjustment, we used the Japanese version (Kitamura, 1993) of the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The final

part of the questionnaire included six items for subjective physical symptoms (appetite, sleep state, fatigue, dyspnea, feeling of numbness, and pain) and a tangible social support scale (Blake & McKay, 1986).

Finally, the physician-in-charge of the participants evaluated their performance status using the criteria of the Eastern Cooperative Oncology Group performance status (ECOG PS). ECOG PS is widely used to measure the level of patient activity using eleven grades (0–4). Also, the physician reported details of each participant's diagnosis, metastasis, chemotherapy regimen, expected prognosis, and other physical symptoms.

Analyses

The descriptive analyses were conducted to summarize the participants' backgrounds and psychological measurement scores. Those with over 30% missing values on the questionnaire were excluded from the statistical analyses. If one or two scores within the subscales of psychological measurements were missing, the averaged scores of the series were substituted into a formula for the total scores of each subscale. Univariate analysis (ANOVA) preliminary analyzed the factors predicting stage of readiness, and categorical regression analysis was performed using all significant predictor variables (p $\leq$ 0.05). Because categorical regression analysis proved only one significant and very strong predictor for stage of readiness, that is, a decisional-balance score, we performed correlation analysis using the decisional-balance score. SEM was performed to confirm the multiple relationships among the significant variables in the results of categorical regression and correlation analysis. As the categorical regression analysis confirmed a strong linear relationship between stage and decisional-balance, we transformed each participant's ordinal response for stage into numeric scale. To obtain a valid model to account for stage, we compare the Akaike Information Criteria (AIC) index of each model. This measure indicates a better fit when it is smaller. We adopted a model with a parsimonious structure and a smaller AIC index. We conducted all statistical analyses using the SPSS software package (version. 11.0) and AMOS software package (version. 5.0.1).

Results

Characteristics of the participants

The participants consisted of 78 males and 27 females. Table 1 shows their demographic and diagnostic data including mean age, gender, diagnosis, stage at diagnosis, ECOG PS, distribution of TTM stage for outpatient chemotherapy and mean time from patients' houses to their hospitals. In the distribution of TTM stage, there were four participants in precontemplation, 42 in contemplation, 22 in preparation, and 35 in action. Because of insufficient number (N $\cdot$ 4) of the participants in precontemplation for multivariate analysis, we excluded their data from the following analyses.

Psychosocial factors associated with the outpatient chemotherapy stage

To explore the differences among patients in the three stages of contemplation, preparation, or action, we reported the mean score of the following independent variables: TTM components, self-efficacy, HADS, physical symptoms and social support (Table 2). Participants in the action stage showed a significantly higher score on pros,

Table 1. Demographic characteristics of the participants.

Mean age• SD	64.52• 9.40
Gender	
Male/Female	78/27
Diagnosis	105
Lung cancer	55
Ad	23
Sq	1
La	18
Sm	8
Stage at diagnosis	
Stage IA	2
Stage IB	1
Stage IIA	5
Stage IIB	13
Stage IIIA	14
Stage IIIB	66
Stage IV	4
Missing	1
Inpatient/Outpatient	37/68
PS (ECOG)	
0	29
1	69
2	6
Missing	1
TTM Stage for outpatient chemotherapy	
PC	4
C	42
PR	22
A	35
Missing	2
Mean time (minutes) from house to hospital• SD	46.19• 32.29 [10–240]

PC: precontemplation, C: contemplation, PR: preparation, A: action.

decisional-balance and the three variables of self-efficacy than participants in contemplation. Participants in contemplation had a significantly higher score on cons and dyspnea than participants in action. For HADS-depression, participants in preparation had the highest score among the three groups.

For TTM components, there were significantly negative correlations between pros and cons (r• • 0.37, p 5 0.001), and between cons and decisional-balance (r• • 0.83, p 5 0.001), and a significantly positive correlation between pros and decisional-balance (r• 0.82, p 5 0.001). In addition, correlations between decisional-balance and both pros and cons were comparatively high (r• • 0.83, p 5 0.001; r• 0.82, p 5 0.001, respectively). Therefore, we concluded that using these three variables for the multivariate analyses would not be useful and that only using decisional-balance as a representation of TTM components would be valid.

Categorical regression analysis was preliminary performed on the variables showing a significant relationship with stage differences in ANOVA, and revealed that decisional-balance was the main factor to explain the differences in outpatient chemotherapy stage

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Table 2. Descriptive data and ANOVA: Mean comparison of outpatient chemotherapy stages.

Measure	Contemplation		Preparation		Action		Total		F(2, 96)	P
	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
TTM components										
Pros	33.67	8.18	37.71	6.00	40.55	6.08	37.00	7.61	9.28	0.000
Cons	39.46	5.95	35.55	4.85	28.06	6.81	34.56	7.84	34.19	0.000
Decisional-balance	• 5.79	10.77	2.16	8.59	12.49	9.87	2.44	12.78	31.87	0.000
Self-efficacy										
ARE	59.39	16.05	64.62	22.69	70.33	16.63	64.42	18.37	3.57	0.032
SCE	49.68	24.73	52.50	22.07	62.94	21.33	54.99	23.54	3.34	0.040
ADE	64.22	17.64	68.94	15.32	79.60	17.45	70.71	18.25	7.88	0.001
HADS										
Anxiety	5.81	4.03	6.10	2.68	5.21	2.95	5.66	3.39	0.52	0.594
Depression	6.12	2.72	7.00	2.86	5.16	2.46	5.98	2.73	3.32	0.040
Total	11.93	5.74	13.10	5.01	10.38	4.54	11.64	5.24	1.98	0.144
Physical symptom										
Pain	27.56	23.11	28.18	25.57	24.00	23.91	26.43	23.78	0.29	0.753
Appetite	1.95	0.74	1.91	0.81	1.60	0.69	1.82	0.75	2.35	0.101
Insomnia	1.83	0.66	2.00	0.53	1.66	0.54	1.81	0.60	2.33	0.103
Nausea	1.45	0.71	1.48	0.81	1.18	0.46	1.36	0.66	2.07	0.132
Fatigue	1.95	0.70	1.86	0.89	1.80	0.68	1.88	0.73	0.41	.662
Dyspnea	1.45	0.63	1.23	0.43	1.17	0.38	1.30	0.52	3.18	0.046
Numbness	1.71	0.77	1.45	0.60	1.86	0.81	1.71	0.76	1.94	0.150
Social support										
Tangible assistance	3.81	2.38	4.50	2.79	4.79	3.32	4.31	2.83	1.21	0.304
Performance status										
ECOG PS	0.79	0.61	0.77	0.43	0.79	0.59	0.79	0.56	0.10	0.991

ARE: affect regulation efficacy; SCE: symptom coping efficacy; ADE: ADL efficacy.

(• • 0.58, p ≤ 0.001; R^2• 0.45). There were no significant effects of other demographic, physical or psychological variables: Affect regulation efficacy (• • • 0.03, n.s.), symptom coping efficacy (• • • 0.01, n.s.), ADL efficacy (• • 0.12, n.s.), HADS-depression (• • 0.00, n.s.), and dyspnea (• • • 0.11, n.s.). These findings suggested presence of a model in which decisional-balance mediated between psychological and physical variables and outpatient chemotherapy stage. Therefore, in the next step of the analyses, we tried to identify the variables that accounted for the variance in the decisional-balance score. Prior to the analysis, preliminary correlation analysis was conducted between decisional-balance and demographic variables (time from house to hospital, stage at diagnosis, expected prognosis, and performance status), physical symptom variables (pain, appetite, insomnia, nausea, fatigue, dyspnea, and numbness), and psychological variables (depression, anxiety and self-efficacy subscales) The results of correlation analysis was represented in Table 3. The analysis showed significant correlations, including time from house to hospital (r• • 0.29, p ≤ 0.01), appetite (r• • 0.25, p ≤ 0.05), nausea (r• • 0.32, p ≤ 0.01), dyspnea (r• • 0.21, p ≤ 0.05), HADS-anxiety (r• • 0.23, p ≤ 0.05), HADS-depression (r• • 0.23, p ≤ 0.01), affect regulation efficacy (r• 0.39, p ≤ 0.001), symptom coping efficacy (r• 0.35, p ≤ 0.001), and ADL efficacy (r• 0.52, p ≤ 0.001). Using SEM, we developed a structural model, which regressed the decisional-balance using these nine

Table 3. Intercorrelations among decional-balance, demograhic variables, physical symptom variables, and psychological variables.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Decisional-balance	–																
2. Time from house to hospital	−0.29**	–															
3. Stage at diagnosis	0.01	−0.02	–														
4. Expected prognosis	−0.13	0.07	−0.12	–													
5. Performance status	−0.10	0.20	0.13	−0.30**	–												
6. Pain	−0.14	0.17	0.02	−0.22*	0.25*	–											
7. Appetite	−0.25*	0.13	−0.03	0.02	0.15	0.31**	–										
8. Insomnia	−0.10	−0.06	−0.03	0.00	0.09	0.25*	0.15	–									
9. Nausea	−0.32**	0.19	−0.09	0.05	−0.02	0.35**	0.31**	0.02	–								
10. Fatigue	−0.15	0.27*	0.03	−0.14	0.12	0.46***	0.47***	0.11	0.40**	–							
11. Dyspnea	−0.21*	0.09	−0.17	0.02	0.15	0.05	0.17	0.22*	0.23*	0.12	–						
12. Numbness	0.10	0.11	0.01	−0.08	0.01	0.17	−0.17	−0.12	0.10	0.08	−0.24*	–					
13. Tangible social support	0.09	−0.14	0.00	−0.04	−0.09	−0.14	−0.01	−0.06	0.02	−0.05	−0.06	−0.02	–				
14. HADS-anxiety	−0.23*	0.12	−0.02	−0.09	0.14	0.40***	0.19	0.21*	0.31**	0.46***	0.32**	0.09	−0.16	–			
15. HADS-depression	−0.23*	0.10	−0.04	−0.10	0.10	0.20*	0.22*	0.08	0.18	0.33**	0.01	0.12	−0.11	0.46***	–		
16. Self-efficacy-ARE	0.39***	−0.15	−0.04	−0.02	−0.05	−0.30**	−0.19	−0.33**	−0.25*	−0.28**	−0.17	0.09	0.23*	−0.42***	−0.42***	–	
17. Self-efficacy-SCE	0.35***	−0.12	−0.06	−0.03	−0.14	−0.18	−0.24*	−0.16	−0.18	−0.16	−0.22*	0.05	0.18	−0.25*	−0.22*	0.53***	–
18. Self-efficacy-ADE	0.52***	−0.24*	0.00	−0.12	−0.10	−0.35***	−0.43***	−0.25*	−0.17	−0.40***	−0.17	0.10	0.29*	−0.47***	−0.43***	0.72***	0.59***

*p ≤ 0.05. **p ≤ 0.01. ***p ≤ 0.001. ADE: ADL efficacy; SCE: symptom coping efficacy; ARE: affect regulation efficacy.

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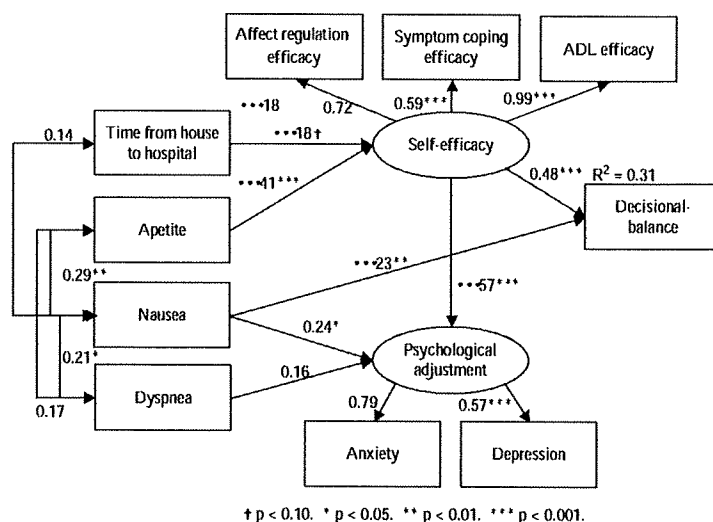t p < 0.10. * p < 0.05. ** p < 0.01. *** p < 0.001.

Figure 1. Structural model for decisional-balance of outpatient chemotherapy.

variables set as predictor variables. First, we assumed two latent variables; one was psychological adjustment, which explained anxiety and depression of HADS, and the other was self-efficacy, which explained affect regulation efficacy, symptom coping efficacy, and ADL efficacy, because there were significant correlation among these variables. We set environmental and physical symptom variables; time from house to hospital, appetite, nausea, and dyspnea as independent variables in the model, and the latent variables; psychological adjustment and self-efficacy as mediating variables between environmental and physical variables and decisional-balance. Also, we draw a path from self-efficacy to psychological adjustment because our previous research indicated that there was significant relationship between them (Hirai et al., 2002). As we removed no significant paths from full path model (AIC• 94.69), which contained all regressed paths to decisional-balance, until the AIC index of model became the least score (AIC• 88.53) among the models, we obtained the final model as indicated in Figure 1. The model excellently fit the data (•^{2} (26)• 36.53, p• 0.16; GFI• 0.93; AGFI• 0.88; CFI• 0.97; RMSEA• 0.05; AIC• 88.53) and accounted for 31% of total variance in decisional-balance by self-efficacy (• • 0.48, p 5 0.001) and nausea (• • • 0.23, p 5 0.01).

Finally, we added a variable, the stage for outpatient chemotherapy, into the model in Figure 1. As we also tested the AIC index from the full path model (AIC• 105.85), which contained all regressed paths to stage, to the model with the least AIC index (AIC• 100.56), the final model represented in Figure 2, was obtained. Fit indices for this model were excellent: •^{2} (37)• 42.56, p• 0.24; GFI• 0.93; AGFI• 0.88; CFI• 0.98; RMSEA• 0.04; AIC• 100.56. Overall, the final model accounted for 40% of the variance in stage for outpatient chemotherapy by decisional balance (• • 0.60, p 5 0.001) and time from house to hospital (• • • 0.15, p 5 0.10).

Discussion

The findings from our study provided encouragement for adopting the TTM in the decision-making for outpatient chemotherapy in Japanese cancer care, although the applicability is limited. We think that the TTM is a very useful and universal framework

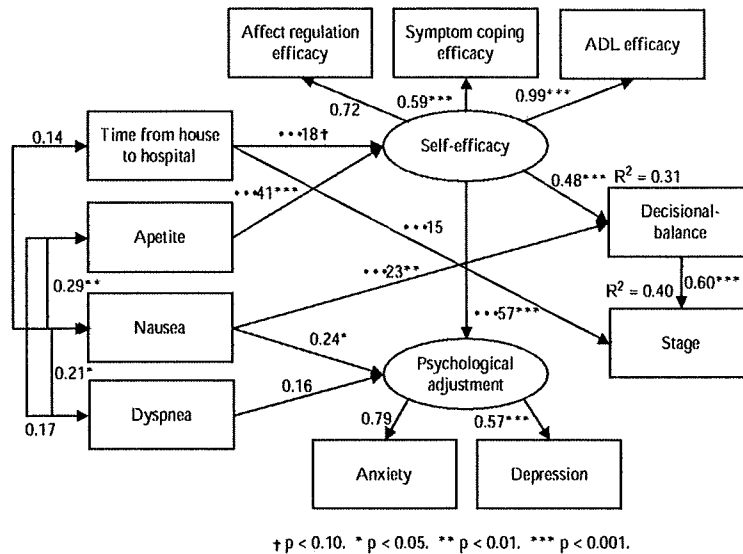† p < 0.10. * p < 0.05. ** p < 0.01. *** p < 0.001.

Figure 2. Structural model for stage of outpatient chemotherapy.

for clarifying behavioral problems, even if they are specific to a certain problematic phenomena in one domestic case.

First, the measurement for stage of change succeeded in classifying the participants into three stages: Contemplation, preparation, and action stages, and there were only four patients in the precontemplation stage. In the hospital where our survey was conducted, all lung cancer patients who were eligible for outpatient chemotherapy were informed about the options and availability of treatment by their physicians, and most of them understood that outpatient chemotherapy was one of their choices. This seems to be why only a few patients were in precontemplation. However, a number of patients (N • 42 [40%]) were still in contemplation and they were reluctant to choose the treatment as the immediate option, although they knew outpatient chemotherapy was an option for them. Therefore, the TTM indicated that a simple explanation of the treatment is insufficient to motivate patients to choose the option and that other factors influence patient decision making.

Second, we obtained a valid structural model, which explained the 40% of the variance in the advanced stage for outpatient chemotherapy. In our structural model, decisional-balance, which is the difference between the pros and cons, explained most of all the variance in stage progressed from contemplation to action. That is, patients who perceived high pros and low cons reached the action stage, while patients who perceived low pros and high cons remained in contemplation. This pattern of change in decisional-balance was consistent with the pattern indicated in basic assumption of the TTM (Prochaska & DiClemente, 1983), the result of the study of mammography (Rakowski et al., 1997), and that of the colorectal screening study (Manne et al., 2002). Therefore these results indicated that adoption of the TTM for outpatient chemotherapy was valid.

Third, in our structural model, demographic, physical and psychological variables significantly predicted the decisional-balance which mainly explained the stage of outpatient chemotherapy. Thus, decisional-balance mediates between demographic, physical and psychological variables, and the stages of readiness for outpatient chemotherapy. This model is also consistent with the theoretical assumption of the

TTM, in which decisional-balance is a mediating factor between the change of stage and other variables. In our model, the time from each participant's house to their respective hospital was the only demographic parameter to have a direct effect on stage, although it was a small parameter. It also showed that outpatient chemotherapy is an inconvenient option for patients who live far from a hospital, for example, more than 1 h away and the mean time from house to hospital was 46.19 min. Also, the reason nausea was a significant predictor of decisional-balance was explained by the fact that it is a significant side-effect of chemotherapy.

The interesting finding of this study was function of self-efficacy including affect regulation efficacy, symptom coping efficacy and ADL efficacy. Patients in the action stage showed significantly higher self-efficacy, and also the latent variable, self-efficacy was the significantly largest predictor of decisional-balance and psychological adjustment including anxiety and depression, and the mediating factor between environmental and physical variables and these outcome variables. Self-efficacy is one of the key components of the TTM (Prochaska & DiClemente, 1984) which explains stage transition, and previous studies showed that self-efficacy of cancer patients mediated between physical conditions and psychological adjust-ments (Beckham et al., 1997; Hirai et al., 2002). Our results are consistent with these theoretical assumptions and previous findings. Therefore, we have two possible explanations of the results. One is that patients' high self-efficacy becomes a motivator to make the transition to the action stage for outpatient chemotherapy and the other is that actual experiences in outpatient service and life in their own house enhanced their self-efficacy. In the first case, self-efficacy becomes a target for intervention to facilitate the transition to outpatient chemotherapy. In the latter case, since the transition to outpatient chemotherapy does not necessarily cause severe physical conditions or disability of daily living to the patients, recommendation of actual experiences for treatment reduces patients' cons and enhances self-efficacy.

We predicted that state of psychological adjustment, including anxiety and depression, would influence differences in stages or the decisional balance in the transition to outpatient chemotherapy. Although univariate analysis implied that patients in prepara-tion were significantly more depressed compared to those in the other two stages, we could not obtain a statistically significant direct effect of depression or anxiety in our structural model. These suggest that the relationship between psychological adjustment and stage is not linear and mediated by self-efficacy, and that psychological adjustment was just a psychological outcome variable. They also implied that the severe depression of patients in preparation might be temporary deterioration in psychological adjustment, and that the actual transition to outpatient chemotherapy might not make patients highly anxious or highly depressed. Therefore, we concluded that recommending the transition to outpatient chemotherapy would not have any negative psychological impact on patients.

There are several clinical implications of the results in this study. First, it is beneficial for medical staff to evaluate subjective components, including decisional-balance and self-efficacy, in patients who are eligible for outpatient chemotherapy. To evaluate decisional-balance, individual differences and inpatients' pros and cons allow medical staff to make an individualized care plan and give adequate information to patients. Second, it may be possible to develop an intervention program combining the TTM-based screening with enhanced self-efficacy. TTM-based screening consists of two psychological assessments, including our single item for measuring the stage and our decisional-balance scale for psychological eligibility

for outpatient chemotherapy. These instruments can clarify the patient's stage of readiness and describe current patient preferences and concerns regarding therapy.

This study has several limitations. The first is that it was cross-sectional in design. Although we could not definitely conclude causality in the relationship among variables, the SEM results have provided strong evidences and insights for future planning of longitudinal studies. Second, the sample of this study was comparatively small and limited to patients in one institution. Therefore, one important suggestion for future research is to use a longitudinal design and multi-center trial. Third, decision making for outpatient chemotherapy is a domestic problem based on the Japanese medical system. If the Japanese Ministry of Health decides to cover outpatient chemotherapy more fully with national health insurance, patients' willingness to transition may change. However, this study shows high applicability of TTM to specific domestic problems, such as outpatient chemotherapy in Japanese lung cancer patients, and that the psychological theory could provide a useful solution. This will encourage psychologists to adapt applied behavioral theory, such as TTM, to other specific behavioral problems in cancer care settings and other medical problems.

Acknowledgments

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A qualitative study of decision-making by breast cancer patients about telling their children about their illness

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Abstract

Objective Many breast cancer patients are troubled about telling their school-age children about their illness. However, little attention has been paid to the factors that encourage or discourage them from revealing the illness. This study explored decision-making by breast cancer patients about telling their children about their illness.

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Methods Participants were 30 breast cancer patients recruited from a regional cancer institution in Japan. Semi-structured interviews were conducted and content analysis was performed.

Results Six preparatory stages of decision-making by Japanese breast cancer patients about telling their children about their illness were identified as follows: *contemplation*, *preparation*, *action-hospitalization and surgery*, *action-adjuvant therapy*, *action-diagnosis*, and *action-prognosis*. We also identified 11 categories of positive aspects and ten categories of negative aspects about revealing their illness to children. The categories of negative aspects with higher frequency were similar to those found by previous research, but categories of positive aspects were unique. The rate of reference to negative aspects in total reduces gradually as the preparatory stage advances, and in *action-diagnosis* and *action-prognosis* stages the balance between positive and negative aspects becomes about half and half.

Conclusions Patients, especially in *action-hospitalization and surgery*, can be expected to tell their children about their illness although they find negative aspects much more compelling than positive aspects and experience great distress. These patients have special needs for support from others.

Keywords Breast cancer · Communication · Children · Illness

Introduction

Parents facing life-threatening illnesses and chronic health conditions experience anxiety, depression, and other emotional difficulties [4, 10] that can impair parenting and place children at risk for problems [16]. Maternal psychological

distress is likely to be greater when there are more children under the age of 21 in the family [3]. In the past, attention has been paid to parents' communication with children when one parent has a terminal illness [17], but the relative frequency of treatable, serious illness in general among parents makes the issue of communication with their children an important and growing public health matter. In Japan, the population-based cancer registries in 2000 showed that the age-specific incidence of breast cancer patients was the highest between the ages of 45 and 49 [12]. In the meantime, the proportion of childbearing women aged between 30 and 34 increased from 2000 to 2005 whereas that between 25 and 29 decreased, and it is assumed that the childbearing age will become higher in the future [19]. Therefore, it is to be expected that the incidence of breast cancer patients who have a child at the time of diagnosis will increase over time. Consequently, the need for support for breast cancer patients who have school-age children will become greater.

For breast cancer patients who have school-age children, it is said to be difficult to respond to their children [7], and many patients who have school-age children feel troubled, especially about telling the children about their illness [18]. However, little attention has been paid to whether, what, and how children should be told about their parent's diagnosis. The responsibility for telling their children about their illness has been left largely to patients themselves [1]. The little research that has been conducted on this issue suggests that when children are told of the parent's diagnosis the children's anxiety levels are lower and communication within the family is improved [13]. It is also said that many children of breast cancer patients seek information about the parent's illness [5]. Previous research shows that there is considerable consistency in the reasons given by patients for either discussing or not discussing a diagnosis with their children [1]. The main reason for not discussing their illness was to avoid facing children's questions and to protect their children from being shocked. Discussion about their illness was also avoided because the children's understanding of the illness was not expected. On the other hand, those women who had communicated in detail with their children thought that their children had a right to know. They also wanted to keep their children's trust and to promote discussion in the family. However, the number of studies of this issue is small and no study has examined the patient's decision-making process about telling about their illness to their children.

We carried out semi-structured interviews taking elements of the theoretical framework of the transtheoretical model (TTM) to explore the decision-making process about telling their children about their illness in Japanese breast cancer patients. The TTM [14] is useful for explaining changes in health behavior and has been used in various programs such as smoking cessation [15], genetic testing

for colorectal cancer [11], mammography adoption [8], and complementary and alternative medicine use [6]. In the TTM, the decisional balance between pros and cons, positive and negative aspects of the behavior, respectively, will account for the state of change observed during five stages: pre-contemplation, contemplation, preparation, action, and maintenance [14]. The idea of TTM that the recognition of positive and negative aspects of the behavior influences one's action can be of some help when we deal with the issue of breast cancer patients telling about illness to their children because a previous study showed that patients who intend to disclose their illness to their children often struggle between positive and negative aspects of disclosure. Furthermore, it is assumed that patients told their children gradually about their illness, but the steps of disclosure have not been shown. It would appear that the framework of preparatory stages of TTM could be useful to explore the steps of disclosure.

Our aims were thus as follows: (1) explore the steps in which Japanese breast cancer patients tell their children about their illness; (2) identify the factors that promote or prevent disclosure of their illness regarded by breast cancer patients having told their children in a different way; (3) consider the balance of factors that promote or inhibit disclosure about their illness in each stage. The ultimate purpose of this study is to develop a support system and tools for breast cancer patients according to their needs.

Patients and methods

Participants

Participants were breast cancer patients receiving outpatient or inpatient treatment and patients under follow-up hospital visit at a regional cancer institution in Japan from April to October 2006. Patients who met the following criteria were recruited: have breast cancer, know their diagnosis, have no cognitive impairment, over 20 years old, have school-age children aged from 6 to 18 years, physically able to be interviewed, and able to communicate verbally. Their primary doctors at the department of breast oncology briefly explain the purpose of the study to patients who meet the criteria above and introduce them to the researcher at the department of psycho-oncology if they accept interviews. The researcher explained the purpose and method of the study in detail and obtained written informed consent from all the participants. This study was approved by the institutional review board of National Kyushu Cancer Center.

Interview procedure

Semi-structured retrospective interviews were conducted by a doctor who specializes in psycho-oncology at a room in

the hospital where patients' privacy was protected. The interviews followed an interview guideline developed by the authors through consideration of the purpose of this study. The interview contained predetermined open-ended questions as follows: (1) How have you told your child about your illness from the time of diagnosis to now; (2) How did you think about positive or negative aspects of disclosure when you considered how to tell your child about your illness. Participants were asked to respond freely to the questions. The interview took about 1 h.

Analysis

All interviews were audiotaped and transcribed. Content analysis was performed on the transcribed data. First, all text data were divided into thematic units (TUs) which are the units of words making one logical sense [20]. Second, researchers and three students of psychology extracted all statements from the transcripts related to study topics such as explanation about illness and factors that promote or prevent explanation. Then, they carefully conceptualized and categorized attributes of the transcripts based on similarities and differences in the content, and made the definition for all categories. Finally, two coders among the students of psychology independently determined how each TU corresponded with each category. They also determined the preparatory stage for each TU that was identified to correspond with any categories. When their coding was inconsistent, they discussed and made a final judgment. The concordance rate and kappa coefficient [9] of the determinations of the categories were used as reliability indicators.

Results

Backgrounds of the participants

There was no refusal to enroll in this study among the 30 participants. Table 1 summarizes the demographic and diagnostic information of the participants.

Decision-making process

Preparatory stages

Most of the patients followed a similar course in the explanation process. Six preparatory stages of explanation of illness were obtained from data as follows: contemplation, preparation, action-hospitalization and surgery, action-adjuvant therapy, action-diagnosis, and action-prognosis. Contemplation was defined to be the stage in which patients intend to tell about illness but do nothing. A patient who told about when she was in contemplation said 'I thought that I have to tell my child

Table 1 Backgrounds of participants

	n	(%)
Patients		
Age (mean±SD)	43	±4
Stage of cancer		
I	6	(20)
II	18	(60)
IIIA	3	(10)
IIIC	1	(3)
IV	2	(7)
Treatment length (mean±SD)	23	±21
Number of children		
1	11	(37)
2	17	(57)
3	2	(7)
Preparatory stage at the time of interview		
Contemplation	1	(3)
Preparation	0	(0)
Action-hospitalization and surgery	2	(7)
Action-adjuvant therapy	0	(0)
Action-diagnosis	22	(73)
Action-prognosis	5	(17)
Child		
Age		
Elementary school (6–11)	26	(55)
Junior high school (12–14)	12	(26)
High school (15–17)	9	(19)
Sex		
Male	31	(66)
Female	16	(34)

about my illness someday. But at that time, I couldn't explain him anything about my illness or treatment'. Preparation is when they do some kind of preparation such as thinking about when or how to tell. A patient who told about preparation stage told 'I asked my primary doctor how to disclose it to my child. And I also discuss about when to disclose it to my husband.' Action-hospitalization and surgery is when they tell about hospitalization and surgery. A patient who explained about action-hospitalization and surgery said 'I told my son that I have to enter the hospital for a while and to have surgery.' Action-adjuvant therapy is when they tell about post-surgical chemotherapy or radiotherapy and side effects of these therapies in addition to the contents of action-hospitalization and surgery. A patient who told about when she was in action-adjuvant therapy expressed 'Before the surgery, I had told her only about surgery. Then after leaving the hospital, I told my daughter about coming chemotherapy. I also told her that, under this treatment, my hair may come off and I won't be able to do housework

enough.' *Action-diagnosis* is when they tell about the diagnosis of cancer in addition to *action-adjuvant therapy*. A patient who told about *action-diagnosis* said, 'I had told him all about my treatment but I hadn't disclosed about my diagnosis. However, I felt that he may be vaguely conscious of my diagnosis, and then, I told him that I had cancer.' *Action-prognosis* is when they tell about the prognosis in addition to *action-diagnosis*. A patient who explained about *action-prognosis* said, 'The prognosis was much more difficult to tell than disclosure about treatment and diagnosis. But at that time, I decided to tell her about the possibility of relapse or death.' Unlike the typical TTM, pre-contemplation and maintenance stages were not applicable for classifying the participants. Instead, the action stage was divided into four smaller stages. This was because telling children about illness is not one behavior but a sequence of behaviors with some steps. Table 2 shows the definition of each stage. It is important to take notice that not all patients went through these steps without missing. For example, some patients told their children about hospitalization, surgery, adjuvant therapy, and diagnosis of cancer from the first disclosure, and these patients are regarded to skip four steps previous to *action-diagnosis*. However, there was no patient who conformed to these steps, such as who told her child about her diagnosis without telling about surgery or adjuvant therapy. It is also important to keep in mind that we did not figure out what each participant explained to their primary doctor, and there may be patients who had not disclosed their prognosis. In total, six participants (20.0%) told about when they were in *contemplation*, three (10.0%) told about *preparation*, four (13.3%) told about *action-hospitalization and surgery*, two (6.7%) told about *action-adjuvant therapy*, 23 (76.7%) told about *action-diagnosis*, and six (20.0%) told about *action-prognosis*. The concordance rate and kappa coefficient of the determinations of the stages by the two coders were 68.0% and 0.40, respectively.

Relevant factors for telling about illness

Twenty-one categories of factors that promote or prevent explanation to children about illness were extracted and

categorized (Table 3). Eleven categories of positive aspects were as follows: *obtaining emotional support*, *obtaining physical support*, *gaining understanding*, *reducing stress*, *improving coping ability*, *fostering sympathy for others*, *fostering comprehension of the situation*, *performing his and her own role in the family*, *reducing concerns*, *fostering self-management ability*, and *strengthening the bond between patient and child*. Ten categories of negative aspects were as follows: *being leaked information about illness by her child*, *increasing stress*, *increasing guilt*, *increasing emotional burden*, *increasing concerns*, *getting shocked*, *refraining from skinship with patient*, *increasing concerns about his or her own health*, *increasing physical burden*, and *being mutually dependent*. The concordance rate and kappa coefficient of the determinations of the categories by the two coders were 80.0% and 0.75, respectively. Table 4 shows example of statements for each category. The categories of reasons for disclosure indicated by at least one third of participants were as follows: *fostering comprehension of the situation* (57%), *fostering sympathy for others* (53%), *obtaining emotional support* (43%), and *improving coping ability* (33%). The categories of reasons for non-disclosure indicated by at least one third of participants were as follows: *increasing emotional burden* (63%), *increasing concerns* (60%), *getting shocked* (57%), *increasing guilt* (37%), and *refraining from skinship with patient* (33%).

Decision-making balance for telling about illness

Table 5 shows the number of TUs of the categories indicated in the respective preparatory stages. The percentage of total categories of reasons for disclosure in *contemplation* was 19%, in *preparation* was 83%, in *action-hospitalization and surgery* was 31%, in *action-adjuvant therapy* was 44%, in *action-diagnosis* was 48%, and in *action-prognosis* was 47%. Categories of total reasons for non-disclosure showed a higher frequency than those for disclosure in *contemplation*, *action-hospitalization and surgery*, and *action-adjuvant therapy*, whereas the opposite result was obtained for the *preparation* stage, although the total number of categories was small. In *action-diagnosis* and *action-prognosis*, the

Table 2 Definition of stages

Stage	Definition
Contemplation	Being interested in telling but not intending to tell about illness
Preparation	Preparing for telling
Action-hospitalization and surgery	Telling about hospitalization and surgery
Action-adjuvant therapy	In addition to the former stage, tell about chemotherapy, radiation, and their side effects
Action-diagnosis	In addition to the former stage, tell about diagnosis of breast cancer
Action-prognosis	In addition to the former stage, tell about prognosis

Table 3 Categories about decision-making balance

Items	Patients, n	%	TU, n
Reasons for disclosure			
Positive effects for patient			
(1) Obtaining physical support	9	30	14
(2) Obtaining emotional support	13	43	39
(3) Reducing stress	6	20	11
(4) Gaining understanding	9	30	12
Positive effects for child			
(5) Fostering understanding of the situation	17	57	25
(6) Reducing concern	6	20	11
(7) Fostering self-management ability	3	10	6
(8) Improving coping ability	10	33	33
(9) Performing his and her own role in the family	9	30	17
(10) Fostering sympathy for others	16	53	35
Positive effects for patient and child			
(11) Strengthening the bond between patient and child	9	30	20
Reasons for non-disclosure			
Negative effects for patient			
(12) Being leaked information about illness by her child	6	20	21
(13) Increasing stress	7	23	13
(14) Increasing guilty	11	37	13
Negative effects for child			
(15) Increasing concern	18	60	61
(16) Increasing emotional burden	19	63	79
(17) Increasing physical burden	4	13	6
(18) Increasing concern about his or her own health	3	10	8
(19) Getting shocked	17	57	38
(20) Refraining from skinship with patient	10	33	29
Negative effects for patient and child			
(21) Being mutually dependent	1	3	3

TU thematic units which are the units of words making one logical sense

balance between reasons for disclosure or non-disclosure was about half and half (Fig. 1). Categories with high frequency differed among stages, especially in the categories of positive aspects. The categories of factors that promote disclosure with highest frequency in *contemplation* were *fostering comprehension of the situation* and *strengthening the bond between patient and child*; the highest frequency in *preparation* was *fostering understanding of the situation*, in *action-hospitalization and surgery* it was *fostering sympathy for others*, in *action-adjuvant therapy* it was *reducing stress*, in *action-diagnosis* it was *improving coping ability*, and in *action-prognosis* it was *obtaining emotional support*. On the other hand, the category of factors that prevent disclosure with highest frequency in *contemplation* was *increasing stress*, in *preparation* it was *getting shocked*, in *action-hospitalization and surgery* it was *increasing concerns* and *increasing emotional burden*, in *action-adjuvant therapy* it was *increasing concerns*, in *action-diagnosis* it was *increasing emotional burden*, and in *action-prognosis* it was *increasing emotional burden*.

Discussion

Previous research found that there is considerable consistency in the reasons given for either discussing or not discussing a diagnosis with children [1]. However, the number of reports about this issue is small and no study to date has examined patients' decision-making process. This is, to our knowledge, the first study to investigate qualitatively the decision-making process of cancer patients about telling and discussing their illness to their children.

The most important outcome of this study is the identification of factors that are relevant to the decision-making about telling children. The reasons for not telling their children about their illness that have been identified in the western literature are avoiding facing children's questions, protecting their children, and not expecting the children to understand the illness. The reasons for telling them are that they think that children have the right to know, they want to keep their children's trust, and they want to promote discussion in the family [1]. In our study,

Table 4 Example of reasons for disclosure and non-disclosure

No.	Example of statement

Reasons for disclosure

(1) I was thinking that if I tell them about my illness, they will help in my daily work, for example they may carry my bags when we go shopping together *(mother of 13-year-old)*

(2) I thought she would support me psychologically. In fact, after I told her about treatment, she wrote me a letter of encouragement *(mother of 9-year-old)*

(3) To hold back about my illness was very stressful because I had to act as if I felt good even when I felt sick *(mother of 10- and 13-year-old)*

(4) He sometimes blamed me for not attending his school event. Then I thought if I explain about my illnes and treatment, he would comprehend the circumstance which prevents me from attending his scool *(mother of 17-year-old)*

(5) I thought that he can understand the reason why I go to the hospital so frequently *(mother of 17-year-old)*

(6) She showed too much concern about my illness and future death because I told nothing about my illness. And thus I thought that I had to explain about my illness accurately and to tell that it is a treatable disease *(mother of 14- and 18-year-old)*

(7) I was thinking that, by telling about my illness, he would come to exert greater control over his healthcare. In fact, after telling him about my illness, he came to care his diet *(mother of 11- and 13-year-old)*

(8) I expected her to get coping ability by encountering the difficult situation of my illness together *(mother of 14-year-old)*

(9) I feel that if I mentioned about my illness, treatment, and side effects, they would intend to help me with houseworks. Indeed, the older child came to take care for the younger child. *(mother of 11- and 16-year-old)*

(10) I expected them to gow up as a sympathetic person through the experience of my illness. *(mother of 12- and 14-year-old)*

(11) I thought we would be able to strengten the bond between my children and I through struggle with illness together *(mother of 14- and 18-year-old)*

Reasons for non-disclosure

(12) I was afraid of my illness being leaked by my child to others such as his friends or their parents because he would not be able to understand my feeling not wanting to ever know about my illness to others *(mother of 13-year-old)*

(13) I felt ashamed to tell my adolescent son about my breast cancer *(mother of 5-, 7-, and 10-year-old)*

(14) I felt guilty about putting a strain on my children both physically and psychologically by disclosing about my illness *(mother of 9-year-old)*

(15) I thought that she would be anxious about my death because she had heard of the word 'cancer' and she had an image that cancer is a fatal disease *(mother of 8-, 10-, and 16-year-old)*

(16) I thought that she would suffer pain by knowing about my illness *(mother of 16-year-old)*

(17) Before I disclosed about my illness, I did not ask him for help. Then I was thinking that if I told him about my illness, he would come to think that he would have to help me in my houseworks and I put a burden on him physically *(mother of 14-year-old)*

(18) I was afraid that she would come to be afraid of heredity of cancer *(mother of 16- and 17-year-old)*

(19) I was afraid that they would be shocked to hear about my illness and would feel a sudden panic *(mother of 9-year-old)*

(20) I felt sorry that if I told him about my illness, he would come to put up with hugging me. *(mother of 9-year-old)*

(21) I thought that if I disclose my illness to my daughter, I would be dependent of her and she would also stick to me *(mother of 9-year-old)*

the top three categories of factors that inhibit disclosure (*increasing emotional burden, increasing concerns,* and *getting shocked*) were cited by over 50% of the participants, and these categories seem to be factors considered by many patients. Our result indicates that the negative factors for telling about illness among Japanese breast cancer patients have some factors in common with those in western countries, especially with respect to the intent to protect their children by hiding from them the information about the illness. It is said that many children of cancer patients seek information about the parent's illness [5]. Our result suggested that the perception of patients can be inconsistent with the perception of their children and that patients are inclined to be overprotective. It is expected to conduct a study of both patients and their own children. On the other

hand, the current study extracted several factors that had not been revealed in previous studies. In western culture, the main reason for telling children about their illness is to respect the children's right to know [1]. In our study, the categories of positive aspects were related directly to the patient's own benefit whereby the patient could receive support, such as *obtaining emotional support, obtaining physical support, reducing stress,* and *gaining understanding.* In Japan, children are regarded to be more dependent on their mother than in western cultures [21], and thus, Japanese patients are thought to be less interested in their children's right to know.

The second important finding is that the proportion of categories of negative aspects in total gradually reduces as the stage advances, and the balance between positive and

Table 5 Categories indicated in each stage

Category	Contemplation	Preparation	Action-hospitalization and operation	Action-adjuvant therapy	Action-diagnosis	Action-prognosis
(1) Obtaining physical support	0	0	1	0	9	4
(2) Obtaining emotional support	0	0	3	0	24	12
(3) Reducing stress	1	1	0	4	4	1
(4) Gaining understanding	0	0	0	1	9	2
(5) Fostering understand of the situation	2	3	1	1	15	3
(6) Reducing concern	0	0	0	0	11	0
(7) Fostering self-management ability	0	0	0	0	6	0
(8) Improving coping ability	0	1	1	0	28	3
(9) Performing his and her own role in the family	0	0	0	0	12	5
(10) Fostering sympathy for others	0	0	5	0	25	5
(11) Strengthening the bond between patient and child	2	0	1	1	16	0
Total number of reasons for disclosure (%)	5 (19)	5 (83)	12 (31)	7 (44)	159 (48)	35 (47)
(12) Being leaked information about illness	5	0	4	3	8	1
(13) Increasing stress	7	0	0	0	5	1
(14) Increasing guilt	0	0	1	0	10	2
(15) Increasing concern	4	0	9	6	39	3
(16) Increasing emotional burden	6	0	9	0	48	16
(17) Increasing physical burden	0	0	0	0	3	3
(18) Increasing concern about his or her own health	0	0	0	0	8	0
(19) Getting shocked	0	1	2	0	27	8
(20) Being reserved with patient	0	0	2	0	24	3
(21) Being mutually dependent	0	0	0	0	0	3
Total number of reasons for non-disclosure (%)	22 (81)	1 (17)	27 (69)	9 (56)	172 (52)	40 (53)

negative aspects becomes about half and half in *action-diagnosis* and *action-prognosis*. In studies using TTM, it is typical that pros have a higher proportion than cons in preparation, action, and maintenance stages [6, 8, 11, 15]. These results indicate that the recognition of patients about positive and negative aspects of telling their children about illness influences how patients tell about illness to their children. At the same time, we needed to divide the action stage into four sub-stages because telling about illness is an action composed of many aspects, and the extent to which

patients told their children varied by patient. This finding that the decision process of breast cancer patients for disclosing their illness can be divided into four steps is new and important. In a previous study, 81% of participants told their children about surgery, 90% told about chemotherapy, and 71% told about radiotherapy, whereas only 50% told about their diagnosis [2]. Among the four stages of action, the contents of explanation adopted by patients in *action-hospitalization and surgery* and *action-adjuvant therapy* are told by many patients to their children according to

Fig. 1 Balance of positive and negative aspects among stages

—◆—Total of Positive aspects —■—Total of Negative aspects